

\* WHY BLESS

# COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

COMMUNICATING TOGETHER

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Theme for this Issue: Independence



# Why Become Independent and How to Do It?

PETER LINDSAY, SHIRLEY McNAUGHTON, ANN RUNNING, MIRIAM RUNNING

*This time we decided to combine our editorial with the feature. In fact, we decided to write the feature ourselves with the help of others so that we could explore the full implications of the topic of independence. We were delighted at the contribution of the other associate editors to this issue and feel particularly fortunate that Nola Millin had been asked to do a presentation on the topic and was willing to share it with us. We were also pleased to find so many other "contributions" by AAC users in previous issues of **Communicating Together**.*

Last spring, when the associate editors agreed enthusiastically upon the theme, "Why become independent and how to do it?" we all took for granted that we *knew* what "independence" was. As the time for producing this issue approached, however, we began to realize that "independence" wasn't as straightforward as we had thought! For our feature article, we decided to involve a number of persons in order to examine several facets of independence and their implications for persons with disabilities. As is our custom, we are giving our attention to AAC users in particular. We began by having a conversation with Ann Running, an AAC user with cerebral palsy in her thirties, and her mother Miriam. We asked them what they thought about the concept of independence and the role it played in both of their lives. Ann lives in a group home and requires total support for her personal care, feeding, wheelchair movement, compu-

ter access, telephone arrangements, etc. In contrast, we also discussed the concept with Bob Gibbons, the father of a 24-year-old verbal woman with autism. Elizabeth is able to look after all her personal needs, walks, talks, sings, accesses books and TV as she desires, and volunteers in the community daily with a support worker. Bob is currently facing the question of what independence means to his daughter. How much "independence" will be possible for her? How can he maximize her opportunities to achieve as much independence as her abilities allow?

In the writing of this feature, we were also assisted by the thoughts of many persons who have shared their life experiences in the pages of **Communicating Together** through the years. Finally we thought about what independence means to us personally. Is it really any different for those of us who (currently) have no major disability and those who have different types and degrees of disability? Is anyone really "independent"? What do we mean by independence, anyway? Why try to become independent? If we decide to try, how do we go about it? And perhaps, the most important question, "What kind of independent person would we like to be?"

## What is Independence?

The dictionary is always a good starting point for a discussion such as this. According to the Oxford American Dictionary (1998), *independence* can be defined as "not dependent or controlled by another person or thing", "self governing". The Funk & Wagnalls Standard College Dictionary (1968) adds such synonyms as "autonomous" and "self-determining". The

*independent person* is "not subject to the authority of another". When we asked Annette Lindsay, wife of Peter Lindsay, and Bob Gibbons for their definitions, interestingly they both gave the same one "being able to make one's own decisions and act on them". Annette and Bob stressed that being able to *act* on one's own decisions is as important as making them. But does the action have to be undertaken solely by the person without any assistance from others, for the individual to be truly "independent"? Ann and Miriam Running talked about similar issues and used terms like "self determining" and "free" to describe independence. They also insisted that whatever independence is, it is important that one strives for it. According to both dictionaries and people then, independence seems to be about being free to make choices in one's life. We seem to feel that it is very important for mature adults to be able to make their own choices and to manage their own affairs.

As we discussed the issue more deeply, the question kept surfacing of whether anyone, speaker or AAC user, non-disabled or able-bodied, was really independent. Is anyone really totally free to make whatever choices they want? What about the constraints of their social obligations, their responsibilities? What about the constraints of family, finances, and conscience? Maybe the only differences in independence for persons who have a disability or who use AAC and persons who are able-bodied are in the kinds of constraints they face and the areas of their lives in which they face them. In the end, we even questioned whether total independence would be, in fact, a positive



thing! Maybe, as the song says, freedom is "just another word for nothing left to lose". And maybe, a life divorced from the interdependence of one's family and community members would not be so great! Finally, before we leave the thought of "interdependence", let's remember the strong programs based on the work of interdisciplinary teams within AAC clinics. Too much "independence" within these settings can be a liability!

### **Independence for AAC Users**

In what follows, we examine areas in the lives of AAC users in which they seem to have varying opportunities for choice and independent action. We explore three areas in particular. The first is the area of *day-to-day personal care and activities*. This is the area where the physical limitations of many AAC users would seem, on the surface at least, to have the most dramatic impact on their opportunities for independent action. The second area is that of *socializing and interpersonal relationships*. Making friends and having satisfying social relationships is fundamental to being human. We have often been told by AAC users that this is an area that is extremely important to them, and that it is one of the most difficult areas for them to deal with.

The final area we discuss is *independence of mind*. This is an area where, hopefully, AAC users have the greatest potential for independence, freedom and choice. We examine the kinds of constraints that seem to operate in these different areas and the extent to which these constraints are a matter of convenience and habit or are, in fact, inherent in the situation.

### **I. Independence in Daily Living Activities**

In talking with Ann Running, we learned of the many choices that she feels are important with regard to dressing, eating, grooming. For an AAC user such as Ann, who is severely limited physically, we know independence can be greatly enhanced through her having choices as to what she wears, what and when she eats, when she gets up and goes to bed, when she has a bath, etc. We recognize the need for schedules within group homes and we know the time it takes for staff to "listen" to an AAC user. We know, however, of group homes in which time is allotted in the schedule for the AAC user to specify her/his wishes regarding dressing, eating and grooming. In group homes where this does not occur, we have to assume that it is either a matter of habit or convenience, not a matter of inherent constraints.

Within the area of daily activities, we cannot forget recreation and entertainment. Technology can play a vital role in this area. As with other activities of daily living however, the understanding and support of care-givers is essential. Environmental controls can provide the capability for opening the door to guests, turning on the television or CD player, and computers offer opportunities for games, art, music, "travel", reading and writing. Care-givers must ensure that the technology is kept in good working order, however, and be available to assist when problems arise. How many AAC users do you know who have equipment that is nonfunctional because of inadequate care given to it by the individual's care-givers?

Independence for AAC users in recreation and entertainment relies as well upon some physical assistance from time to time. And of

course, freedom of choice in this area is critical. Selecting what TV program one watches, what CD one listens to, what movie one goes to see can make all the difference in one's feeling of "independence"! When it comes right down to it, independence in daily living activities may simply require care-givers *taking the time to listen*, and underlying this, *recognizing and respecting the AAC user's rights and wishes!*

Perhaps most important in relating to independence in daily living activities is the opportunity to choose where one lives. In Ontario at the present time, supported housing for AAC users is in very short supply due to a freeze on government-supported housing initiatives. Most of the AAC users we know feel they are lucky to *have a place to live*. Some are satisfied with their living arrangements. Many others would like to make a change, but that option is not available to them. For some, the need to move is urgent due to the poor health of family members who now care for them. But no residential openings are available to them. In situations such as this, independence is impossible. The feelings of AAC users in these situations are those of being totally dependent upon the decisions of others. In this case, the dependency arises from government policy that disregards the needs of individuals who are unable to finance their own living arrangements. Their dependence is of the most formidable kind; it is inherent within the societal structure.

Second in importance to an overall sense of independence for many AAC users, is the ability to select and direct their care-givers. Pilot programs in Ontario are giving the authority to manage



their care-giver staff to a small number of individuals with disabilities. Funding for this purpose is directed to the individual, who in turn is responsible for hiring, training, or discontinuing the services of a team of care-givers. This beginning of economic "independence" is a very positive step. It can only be hoped, it will become available to many more persons with disabilities who are prepared to assume the responsibilities involved in order to gain this type of independence. It is an important "how to" when it comes to independence in one's daily living.

## II. Independence in Socializing and Interpersonal Relationships.

The area of friends and social relations is another very important one for many AAC users we know. In far too many instances they have very limited opportunities to make friends with peers, be they able-bodied or physically disabled. For those living at home with their family, the circumstances that made it difficult for them as children to have a wide range of experiences (difficulty of transporting a wheelchair in a family car, inaccessible homes of friends, limited public transportation, energy and time of family members) become intensified as parents grow older and siblings have increased responsibilities with their own families. Opportunities for independent socializing are practically nonexistent for many AAC users living at home. Even when social events are attended without family members, it is usually in the company of a paid care-giver.

For those living in residential settings, staff shortages and reduced transportation services are limiting the kinds of personal outings that used to be possible before the funding cuts in Ontario. Family

weddings, visits to former school-mates' residences, social gatherings with other AAC users, are all becoming more rare, as the mechanics of getting to locations in other districts and personally paying for care-givers make all but occasional outings impossible.

A revealing indication of the range of friends that are possible for an AAC user can be seen by listing those who are considered friends and examining how often they are seen. All too frequently the "friends" are close relatives, professionals who are currently or have in the past worked with the AAC user, relatives of these professionals, and volunteers. Few are able-bodied peers. Few friends with whom the AAC user has regular contact are other AAC users. Often fellow students or fellow residents from many years past are considered friends, even though there has been no contact possible since leaving the school or residence. The opportunities to see *any* friends are rare and visits with other AAC users are often only yearly or biennially. The opportunity to make a date independently or to see a friend independently rarely if ever exists for many of the AAC users we know.

Even "talking" with a friend independently can be next to impossible. This has been one of the strong motivating forces behind the work by the first two authors to develop BlissInternet. Other software for Blissymbol communication via the Internet is being developed in The Netherlands and Sweden. The goal with this software is to ensure that socialization is not dependent upon physical access or upon print literacy. In time, as more AAC users gain access to the internet, it is hoped that their independence in socialization will be increased, at least within the elec-

tronic medium. For those who are print literate and who have computers, this is already beginning to happen. A wonderful example appeared in the March, 1998 issue of **Communicating Together** in the feature article by Anne Abbott, *Sex and the Woman with Disabilities* (pp. 4-6).

Ann Running is *making* the opportunities to socialize more and to enlarge her circle of friends. She, along with her mother and the second author of this article, are initiating a "Friends" music group in Toronto. The Ontario Federation for Cerebral Palsy is providing the funding for a pilot program, and letters of invitation are in the mail as we write this piece. Ann was impressed with the Friends music group of Kitchener-Waterloo, both in hearing them and in reading about them in the Winter 1998 issue of **Communicating Together**. She decided she wanted to belong to such a supportive group of friends in Toronto and took the action needed to make it happen. Ann also takes action on Thursday mornings when she becomes a "greeter" at the Bloorview-Macmillan Centre. There, she and her mother meet parents who want to talk about their children's problems and have discussions in which Ann's and Miriam's experiences can be shared. We know of another AAC user who volunteered in a hospital as a guide during his summer community college vacations.

These types of opportunities offer a little bit of independent socializing. Even so, for the person who is not physically independent, these outings still require a companion, be it a family member, a volunteer or paid staff. One need hardly ask the question, "Why become independent?" in this context. Who



among us does not cherish the intimate moments we have one-on-one with friends? "How to do it?" for AAC users with severe physical impairments has to be responded to by "finding the right technology"! Whether it be light tech. (a spelling, picture or Bliss communication board) or high tech. (computer, VOCA), independence can only be gained by an AAC system that matches the individual's capabilities, and is "friendly" to friends!

Often, the level of technology that is preferred will depend on the situation. For one-on-one conversations with friends, frequently the quiet private communication board is preferred. When socializing in a group situation on the other hand, the VOCA may be much more appropriate. Independence relies on being versatile and proficient in the technology that is used. To quote Ann, "I count on my Freestyle computer to write my own ideas and say what I think and feel. I want to plan my social life and what I do. In restaurants, I love to place my own order from the menu using my computer!"

As we discussed peers as friends, we wondered how the situations of AAC users who attended integrated versus segregated schools during their formative years, differed by the time these individuals were in their thirties. We welcome any thoughts in this area from our readers. For all of us, how many of our school friends remain with us throughout the years? What is the situation for those attending segregated schools or classes? What is the situation for those integrated through their school years? For many of our AAC users in Ontario, integration was not an option during their early school years, so comparisons were not possible.

As we thought about socialization independence, we also thought about sexual independence and the many challenges faced by AAC users in this area. The article referenced above by Anne Abbott and other articles in the March 1998 issue of **Communicating Together** focus on this topic. This issue of our magazine was particularly insightful. For current subscribers who do not have this back issue, we would be pleased to mail it upon request. Independence in this area begins in having knowledge and in being able to communicate one's feelings. The personal sharing offered by the contributors to the March 1998 issue of **Communicating Together** make a valuable contribution in the area of sexual independence for AAC users. Their ideas relate very well to the last area of independence we are considering here.

### III. Independence of mind

The body may be constrained but the mind can be free. We had to begin this way, for it is in this area of independence that AAC users can have an equal playing field to that of able-bodied persons, if we but ensure that their communication system is adequate to meet their potential. Ann and Miriam Running gave us many examples of the intellectual independence that is fostered in the Adult Education program at Seneca College, which Ann attends four days a week. How critical to this independence are ongoing educational opportunities and ongoing upgrading of communication and literacy abilities. Here, technology plays a vital role, but so does the enlightened instructor! For Ann, this person is Sherri Parkins.

Sherri Parkins is a very gifted teacher and caring human being. She gives much more than literacy instruction in her program for AAC

adults. Knowing the independent spirit of many of her students, Sherri's greatest contribution is in providing the environment in which *independence of mind* can develop and flourish! Group discussions about the local and international news, advocacy issues in the Toronto area, and the challenges of independent living, ensure that this educational program relates directly to issues in the lives of Ann and her classmates. Instruction relating to literacy, communication and each individual's technology is individualized, but much attention is given to group activities and socializing.

Throughout the years, we have seen many examples of independence of mind expressed in the articles written by and about AAC users! We thought we would select a few from past issues of **Communicating Together** to illustrate the variety and depth of their thinking on this topic:

#### Ruth Sienkiewicz-Mercer (1991)

From her book co-authored with Steven B. Kaplan, *I Raise My Eyes to Say Yes*, p. 224-225

"Now I am getting an education. I go grocery shopping for myself, and my personal care attendants ask me what I want to do and when I want to do it.....All of the people still living at the State School should be moved out, and all of the money now being spent at the institution should be directed at the handicapped living in the community. The State School should be torn down brick by brick."



### **Andrew Murphy (1992)**

"What does the future hold? Everyone thinks about the future. We all hope and try to plan for a better life. What that means to each of us will vary. I am no different and spend a lot of time thinking about my future. Thinking about finishing my education so I can get a job. Thinking about developing the skills so I can live on my own, with help of course, thinking about making new friends and staying in touch with my old friends, thinking about seeing more of the world and how I can make it a better place."

### **Kari Harrington (1993)**

A frequent contributor to **Communicating Together**.

"The most hurtful thing to me personally was when I was first staying here and asked one of the attendants to be careful of my equipment. I have devices and gadgets that need special care when handling them. She seemed to be treating them roughly. She called me a 'fuss budget'. When I printed out on my Epson how easily these things can be broken, how hard it is to get them fixed sometimes and how I didn't want to have to do without them, she just laughed at me and walked away. It really hurt my feelings. I know I was especially sensitive at that time, however, I think a person who relies on devices has the right to expect that their equipment will be treated with the same respect as they are."

### **Nola Millin (1993)**

Associate Editor, **Communicating Together**.

"If you are a child, adult, parent, teacher, clinician, able-bodied, non-verbal, regardless of who you are or what condition you might have, you will experience change. Isn't it wonderful? Everybody is equal when it comes to the experience of change. As I already mentioned, what we differ so drastically in is our ability to cope, or in some cases not to cope, with change. It seems like our society is facing a greater amount of serious changes than ever before and from what I'm seeing, a lot of people are having difficulties in knowing how to cope. . . . I'm going to look at the negative side of change and discuss positive ways that either I have coped, or that I have seen others cope, with change. I'm not a professional counsellor but I do feel that I have witnessed enough loss in my life, or in the lives of others, to be able to share some of my experiences."

### **Rev. Lee Mehrlich (1994)**

"It is difficult to know that someone you love is very sick. What seems to be helpful is to hope he or she will get well and to remember that person for who they are, for their strengths, their smiles, and the many ways that they urge us on . . . . Mother's death is a very big sadness for us. There is so much in her that we do not want to let go of her. All my life she has been an advocate for me. Because I could not speak, she was my mouth . . .

Because of my Blissymbolics and Touch Talker, I was able to have an active part in Mom's funeral. I met and communicated with people who came to support us in love. . . . My experience showed me that being able to communicate helped me to feel independent and more in control at this very hard time."

### **Susan Foster Odell (1995)**

In memory of Susan Odell, Carol Lynn Katsios wrote:

"Sue was born with cerebral palsy. She couldn't walk. She couldn't talk. In fact, Sue couldn't do the things that most people take for granted every day. When Sue awoke to begin her day, she waited to be washed, dressed, then lifted into her electric wheelchair. When hungry, she waited for someone to feed her. Every moment of Sue's life echoed the same theme — wait. When Sue went out, people stared at her. As she drove her wheelchair, her arms and legs had involuntary muscle spasms, and sometimes flailed wildly. And Sue drooled.

But inside that body that didn't work was a quick intelligence, a keen perception and an indomitable spirit. Sue packed more living into her short years than many people do in much longer lives. Even with her physical limitations, she had a job with a community awareness program. Even though she couldn't talk, Sue was a trained public pre-



sender . . . . Sue never questioned her lot in life. She never asked for concessions because of her disability. She lived her life in quiet dignity, asking only of others that they treat her as an equal."

### Treena Guy (1995)

"Sometimes when I am out with friends, strangers ask the people that are with me if I want something. It really frustrates me as it is as if I was not there sitting beside them. I know that they are afraid to talk to me because they think that if they don't understand what I say, I will get upset. No way would I be upset if at first they didn't understand. It makes me happy when strangers try to talk to me."

### Justin Clark (1996)

Described by Shirley McNaughton

"At the age of eighteen (legal age of adulthood) a Rideau Centre psychiatrist certified that Justin Clark was able to make his own decisions about matters affecting his life. Justin's father, Ron Clark of Ottawa, concerned for his son's future, filed court action [1983] to have him declared mentally incompetent under the Ontario Mental Incompetence Act. In the ensuing highly publicized week-long case, Justin told the court, through his Blissymbol board, that he believed he was capable of making choices for himself.

At the end of the trial, Judge Matheson challenged Canadians to look beyond an

individual's physical disabilities to his or her total capacity for learning and development in a decision which was not only a legal landmark but the seal on a triumph of the human spirit. When asked, 'Who will make decisions for you, Justin?', he responded, "I"!

### Paul Marshall (1998)

Associate Editor, **Communicating Together**.

"As I look back over my life, I always had an inner drive to be as independent as I could. I am not sure where we get our inner drive to do or not to do things. In my case, it is *not* an ego trip or "I will show them" (well, maybe a little!) frame of mind. It is just that I enjoy doing things for myself even if I have to struggle and put more energy into a task."

And there are many more examples that space limitations prevent us from sharing!

### Conclusions

So, why become independent? Perhaps, rather than respond to our original question, we should first change it slightly to "Why become an independent person?" For it is the full person that counts, not one facet of the individual that may or may not be "independent". In fact, the writing of this article has lead us to consider what we should have been thinking about all along "What is an independent person?"

There are many examples above and in the pages of **Communicating Together** since our first issue in 1983. An independent person is one who is confident in who he or she is and who takes

every opportunity available to make choices about his or her life. *And when the opportunities are not there, they make them happen.*

*Why become independent?* In order to be fulfilled as a person, to realize our unique capabilities and make our unique contribution in our world. *How do we do it?* Interestingly, it is through an interdependence with others! For it is only through interacting with others that our potential is realized. Many AAC users teach this to those who interact with them. Isn't it wonderful that as we relate with each other, both partners can be contributing to the independence of the other? And in this regard, there is no difference between those with a disability and who use AAC, and those who are able-bodied! We share much more sameness than difference.

*We want to remind you again as we did in the last issue that this is our last year of publishing **Communicating Together**. There will be four more issues published after this one. It has been a wonderful and satisfying experience for all of us. We particularly enjoy the lively and invigourating annual editors' meeting where we argue and debate what are the most important issues in AAC that should be covered in **Communicating Together** in the upcoming year. We are going to try to make this last year our best! We hope you will continue to subscribe for one more year.*

*In the next issue, the theme is "Dreaming — everyone has the right to dream!"*

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# AS COMMUNICATION CHANGES

## Smelling the Flowers

ALDA STEPRANS



Alda Steprans

*Those of you who read **Communicating Together** regularly know that Audrey McGee is a regular contributor. She suffered a stroke some years ago. Because she is slow to learn she did not do well in a rehabilitation setting, but continues to enjoy learning at the*

*chronic care hospital she lives in. Audrey uses a wheelchair and relies on caregivers for all her needs. Although Audrey cannot speak, she can spell to make her needs known.*

**I**t's important for me to be as independent as I possibly can be. I like to do as much as I can for myself. For some things I am very dependent on others. I need to be washed, dressed, helped out of bed and listened to. But, I can feed myself, paint, make my own decisions and communicate using my letter board or Light Writer.

If I wasn't as independent as I now am, I could not get to the oil painting classes I attend at the Pat Arato Aphasia Centre. I love going there! It was only because I was independent enough to use Wheeltrans that I even got the chance to go. Because I cannot speak, other people have to help

me connect to others, for example call Wheeltrans to arrange a pick-up time, but I am happy that I can direct those who help me. I am *independently minded* enough to communicate what it is I need or want.

Because I have an electric wheelchair and know how to use it safely, I can go to the corner store, out to the hairdresser's or down to the park on my own. I even went to the hardware store around the corner to buy some hooks. My wheelchair has opened up my world so that I'm not having to be in the same place all the time. I get to see new places and experience new things. I enjoy that. It is much more exciting than being in the hospital I live in all of the time. I love to see the flowers and trees in the gardens of my neighbourhood.

AUDREY MCGEE

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## READERS WRITE

*We did not have space for a **Using Technology** section in this issue. We did however receive an interesting comment from a highly experienced AAC clinician and one of our readers, Shelly Deegan. It is interesting to note how compatible Shelley's remarks are with Tracy Shepherd's (see page 9-10).*

**I**would like to make the following comments. There were frequent negative comments re the use of technology with young children in the Summer 1999 issue of **Communicating Together**. I feel that this needs some clarification. I often wonder what people mean when they lump everything under 'technology'.

There is a huge difference between using a computer system or a very sophisticated voice output device and some introductory voice output device with a young child. Also, use of a voice output device does not preclude the use of non-technical means of communication. What ever happened to the philosophy of 'total communication'? It was widely acknowledged that the use of signing and graphic communication worked well together to enhance overall communication. *Why shouldn't technology be part of the mix?* There is no better way to teach initiation and interjection skills to children than through voice output. I have very young nonspeaking visually impaired students who cannot

access graphics easily and voice output has been the best means to open up communication opportunities for them. I imagine that you are worried about devices being used exclusively. I don't think that the approach should be to shy away from technology — technology is here to stay. We should focus on how best to use technology, how to make it work the best for our young clients to help teach language, communication, social skills. Let's make technology work for us, rather than fearing how it is impacting on the field of AAC and AAC users.

Shelley Deegan  
Chedoke-McMaster  
Technology Access Centre  
Hamilton, Ontario



# CLINICALLY SPEAKING

## Baby Steps Toward Independence

TRACY SHEPHERD



*Tracy Shepherd*

**T**he goal of independence is an overriding for our clients. There are so many ways to explore options for independence and each individual defines their independence differently. It is quite exciting to see clients able to do something independently with or without technology that they were previously not able to do. This becomes the highlight of clinical visits when we can train a skill and come back the next time to see the skill perfected and the client asking us for more information, "How do you do. . . ?" This keeps us on our toes. For children the steps toward independence are slow and small but as individuals enter adolescence and adulthood they are able

to make more of their own choices and gain their independence more quickly. It is interesting to see the transition.

Clinically speaking there are so many wonderful devices and computers out there for our clients. Many of these options promote our clients to be independent and open up opportunities for them. Let's talk about computer technology. Everybody and their brother is making devices that can do anything from calling to order a pizza to doing the dishes when you are finished eating it. The devices and computers are becoming very sophisticated. Devices literally will open doors for individuals with communication difficulties and allow them access to the world outside which they didn't have previously. The Internet alone has been remarkable. Individuals with disabilities who for a long time needed assistance to do their banking and shopping and communicating can now go on line with adapted access and do these functions themselves without a facilitator.

In more recent past, adapted access to the Internet has improved making the process a bit easier for individuals with physical access issues. It certainly opens up new worlds for them! E-mail is another avenue that allows access and communication. As we know AAC users are typically a bit slow in their communication exchanges. Using e-mail nullifies the difficulty in having to wait for a reply. When using e-mail you get to the response when you get to it. With

the pressures of time removed this must take a tremendous strain off AAC users and help to make communication exchanges more relaxed.

Low technology is really amazing in providing independence with promoting more intimate conversations and speed. Most of the AAC users I know are faster and more comfortable when having a one-on-one conversation using their low-tech systems. And let's be honest - they don't break down. One user I know has a Blissymbol board and communicates mostly with her mother at home. The board must have hundreds of Blissymbols on it *but* they are so well used that the symbols are actually worn out. They haven't bothered to replace the symbols since they both know what the symbols are from memory. Needing to use low-tech, you might say, does not promote independence. To the contrary, one must always have a communication partner to have a conversation so there is always the need for another person to "assist".

Voice output certainly has its place. There are times when folks need to give a speech or use the telephone and these occasions lend themselves well to the use of a VOCA. These seem to be more "out in public" kinds of uses where projection is a concern. Multi-modal communication is the most effective way to achieve the highest level of communication possible. I am lucky enough to have some friends and colleagues who demonstrate the epitome of



these skills. Given the many modes and systems for AAC there are many options for independence available to individuals. It seems to be getting the right combination for each user and identifying the best mode for each situation that promotes the most independent communication possible.

I would like to speak to the selection of vocabulary that goes into the voice output devices and communication displays. There is a real struggle on the part of those trying to gather this information. In a lot of cases the non-verbal individuals don't have the input they should about what goes onto their communication displays. I was once involved in a discussion with a colleague who was opposed to there being swear words on a low tech display of a high school student. Their rationale was that it was not appropriate for that student to use those words in the high school environment. *Well* don't get me started! I certainly feel that any vocabulary available to any other high school kid should be available to any kid who happens to use augmentative and alternative communication. The thought of this individual is that those words should not even appear on the display. This really makes my blood boil. I *strongly* feel that while kids probably should not be using foul language, the truth of the matter is that *they do!*

We need to allow kids using AAC the opportunities to find out when it is appropriate to use that language and when it is not. Let them experience the natural social consequences of using foul language at inappropriate times. Live and learn! After all, that is how all other kids learn when they can use that language. Here is a prime

example of independence. Of course, AAC users need to be intimately involved in the choice of vocabulary available to them. We really need to make a big effort to include them in this process and, damn it, we need to give them the opportunities to swear if they want to. I have a hunch that they are probably swearing at *us* if we don't include them in the process.

Other issues around independence and vocabulary selection include the need for the younger child who is not yet literate to have a facilitator program all the vocabulary for the child. This really takes the independence away for the child and vocabulary often doesn't get updated and refined often enough. Vocabulary needs to be constantly reviewed and updated with as much involvement of the child as possible in order for children to have appropriate opportunities to communicate. This issue is eliminated when those who have acquired literacy skills can program their own vocabulary. So there are some natural barriers requiring attention regarding the selection and programming of vocabulary.

I once had a teacher ask me about a child who had a Touchtalker, "How many times a day do you want Susie to use this thing?" Somehow the idea of communication and independence seems to get lost in the glitz of the technology. My answer to her was of course "six and the rest of the class can only make six attempts at communication throughout the day as well!"

We have come so far with helping individuals communicate and with bridging a few gaps to independence. There will always be barriers but together we can help to resolve them one issue at a time.

## COMMUNICATION MATTERS

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NOLA MILLIN

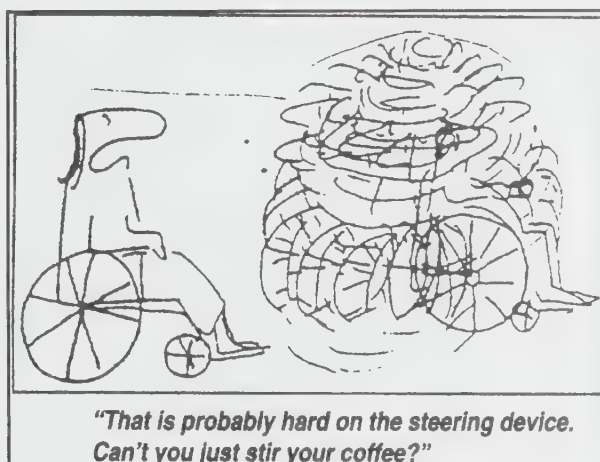


Nola Millin

*This article has been adapted from a presentation I gave about independence. Whenever I give a presentation, I use a computer hooked up to a multi-voice. The multi-voice has 10 different voices so every so often, during a presentation, I will use a different voice to make a comment. Some of the comments have been retained and appear in brackets in this article.*

We might laugh at the cartoon shown here but to me the guy who's spinning around in circles is showing some independence. I'm going to share some of the ways I feel that I have become independent, and how my independence has helped me achieve some of my dreams.

Independence has always been an important part of my life. Independence is often thought of as relating to the things a person can do for himself or herself. Although this is a good definition, it's limiting, especially for those of us who have disabilities. There are certain tasks I cannot do for myself, but I'm still very independent. (Independent is a nice way of saying she is stubborn.) Someone named Grenville Kleiser said, "Learn to depend upon yourself by doing things in accordance with your own way of thinking." When I came upon



that quote, I thought it described independence in a way with which I could fully agree. I have been doing presentations for many years and quite often I have said that being independent is a state of mind. It is being in control of your own life and thinking for yourself. That sounds simple, but I'm finding for many people that it isn't an easy task.

I give my parents a lot of credit. They raised me to be quite independent. My mom started allowing me to make simple decisions at an early age. She would give me choices. By doing this, she was allowing me to make the decision, yet she tried to eliminate my frustration of not being able to verbalize my decision. For instance she would say, "For lunch you can have, a peanut butter, a ham and cheese, or a tuna sandwich." Then she would repeat each one and wait for my "yes" or my "no". As I grew up, like every child, I was allowed to make more and more decisions. Yes, my mom allowed me to make some foolish decisions to teach me that there are consequences to the decisions we make.

What does the ability to make decisions have to do with being independent? My answer is everything! If I want to be independent, then I can't go around asking people for advice on every decision I make. Yes, there are some situations when I need the advice of others before I make the final decision. We pay certain professionals, such as doctors, lawyers, bankers, and so on, to give us advice on important matters. When I get advice from someone, I've learned to weigh the pros and cons before making the decision, *myself*.

I'm so thankful that my parents took the time to teach me how to make decisions and to be independent since, unlike many people, I haven't had my parents



with me for most of my life. I have been forced to be independent and make a lot of major decisions on my own. For those of you who don't know me at all, you need to understand my life hasn't been typical. I lost my father ten days prior to my seventh birthday. My mom died when I was fourteen. I remained with my stepfather until he died — when I was seventeen. After the death of my stepfather, I had a decision to make, since I'm an only child. I could move to the States and live with relatives, or I could stay in Windsor, move out on my own, but pursue my education.

I decided to move into A.L.P.H.A. (Apartment Living for Physically Handicapped Adults). A.L.P.H.A. is like any apartment building, except that there are attendant care staff in the building at all times. They help the tenants be as independent as we can be. Again, I thank God for the training and preparation I received from my parents. When I was twelve, my mom had started leaving me home by myself for a few hours. By age fifteen or sixteen, I stayed by myself from the time I got home from school until the time I went to bed. My supper was a cold plate. I had to take care of myself during the entire months while my stepfather worked afternoons. We had a couple of neighbours whom I could call if I really needed help, but I didn't call them that much. I learned to do things for myself. Another thing that my stepfather did that helped me learn independence was that he often allowed me to tell him what I wanted for supper. My stepfather was involved in running a restaurant, so he would come home from

work, spend a few hours with me, make my supper, then he often went to the restaurant. Since he was only cooking supper for me, he allowed me to choose what I wanted him to make. Since I'm a diabetic I have always had to eat a well-balanced meal, which meant my stepfather made very good meals for me. He was the cook in the family. This preparation was very useful when I moved into A.L.P.H.A.

At A.L.P.H.A. all tenants direct their own care, which means we have to instruct the staff on how we want tasks done, including how we want our meals prepared, if we can't prepare meals for ourselves. In my own apartment, and around people who are close to me, I'm able to feed myself in a unique way. Since I can't hold silverware, I feed myself by taking food off my plate or out of a bowl, by bending over and putting my face down to it. Sometimes I get pretty messy, so that's why I get people to feed me when I go out. *You should see her eat chocolate pudding; it's pretty disgusting. She gets it up her nose and everywhere.* Feeding myself in such a different way is just another example of how I make myself independent. I came up with this motto years ago, "I might do it a different way, but I get it done!" That has basically been my motto for life. So what if I get food on my face, and up my nose, and down the front of me, as long as I feed myself. Hey, I probably stay cleaner than a lot of people who use silverware. So, when I moved into A.L.P.H.A., at least I was a little prepared for independent living.

Being independent means taking responsibility for whatever

you do. Believe it or not, Donny Osmond reveals an attitude that I can relate to. He says "My father instilled in me the attitude of prevailing. If there's a challenge, go for it. If there's a wall, break it down." *I can't believe she just quoted Donny Osmond, her teenage idol from many years ago!* Anyway, I have broken down many walls in my life because I'm so independent. I truly believe that being independent has given me a lot of self-confidence. Either that, or I'm just simply crazy and don't know any better.

My independence was first tested when I was slowly integrated into a regular high school. I ended up having to go to a high school that wasn't at all accessible, but it was the only school that would accept a student with my type of disability. That inaccessibility factor was overcome with help from the football team. I had guys carrying me in my wheelchair up and down flights of stairs. *Not that she minded it! There are advantages to being in a wheelchair, you know. And boy, were the guys cute!* I managed so well at high school that I went on to University of Windsor. I now have a B.A. in Psychology and another B.A. in English.

While at university, I developed another way to make me more independent. I began writing letters to my professors and different people I needed help from. Because of my speech impairment, I have learned that written communication is very effective for me. I have learned that time is a valuable commodity, so I need to respect the individual's time. I realize that it takes me more time to type my response into my



computer, even though people say I type pretty fast with one finger. I also point to words and letters on my word board at an amazing rate. I try to make the communication as easy and as fast for the other party as I can. Many professionals have given me their fax numbers, which is another means that I can be independent. I can communicate by myself through fax. I'm able to talk on the phone with my voice output computer but people have to really listen. I just find communicating through fax is better for me when I need to get something important across.

You might be wondering what all this has to do with being independent. My answer is, a lot. First of all, I am able to communicate with my doctor without having to have another person with me by writing him letters or sending him faxes. Besides allowing me to be independent, it assures confidentiality. Even though I have some close friends, I don't want them to know everything about me. I don't know many people who would want a third party sitting in on some of their conversations with doctors. By writing a letter, the doctor at least has an idea of my problem. Then he can start asking more specific questions. I write letters when I go to the bank or elsewhere in the community. I really feel each person should be as independent as his or her disability will allow. I know people who use their disability as an excuse — "I can't do that because I'm disabled and I might get hurt." Guess what, folks, I haven't allowed my disability to stop me from doing too many things. My independence (*It's stubbornness, I'm telling you*), has helped me to pursue new adventures.

I now have my own business. I used to work at Participation Industries, which is a sheltered workshop for individuals with physical disabilities. While at the workshop, I was approached by a guy who was instrumental in getting the Opportunities Fund established. A component of the Opportunities Fund is that they will pay a person with a disability the start-up cost if the person establishes a viable business. This guy told me about Opportunities Fund before it existed. He thought I would be a good candidate for it. He knew the frustration I was facing, and he could tell the workshop wasn't the answer for me. Initially, I wasn't interested in having my own business. My first reaction was, I can't run my own business; I don't have any idea of what I can do that will allow me to earn an income. I had become my own worst enemy. Someone named Alan Bennett said, "The great advantage of being in a rut is that one knows exactly where one is." Looking back now, I was in a rut. Although I was bored, I was complacent. I feel complacency can be very dangerous, because when we get complacent, we tend to ignore new ideas and new possibilities. At least I do. And I wasn't going to consider the idea of becoming self-employed. I kept working at the workshop and liking it less and less.

One day, some time later, another person mentioned the Opportunities Fund to me again. That time I was open to at least looking at it, so I applied. I still wasn't sure what type of business I would do. Something inside made me realize that I was already doing two things I really enjoyed. One was my speaking engagements and the other was desktop publish-

ing. I went through the needed steps for Opportunities Fund and my business plan was accepted. My business is comprised of motivational speaking and sensitivity training, as well as a little desktop publishing in between speaking engagements. Again, I truly believe that because I have always been independent, that I'm capable of running this business. As I said, there are certainly tasks that I need help with. The important part though, is I'm able to run my business, know when I need help, and organize getting that help.

As I conclude, I want to make something very clear (*Doesn't she talk a lot for someone who has a speech impairment?*) I don't want anyone thinking that by being independent they have to live by themselves, go to school, have their own business, or whatever. These are just some of the things I have been able to do. It doesn't make me any better than the next person. Being independent just means taking some charge in your life, trying to accomplish the tasks that are important to you. We each have something we can do. For me, being independent allows me to live my life to the fullest, and gives me the self confidence to know, that with the Lord's help, I can deal with whatever lies ahead. I hope that everyone who reads this is independent in some way or other. I'll leave you with one last quote. Mother Teresa said, "We ourselves feel that what we are doing is just a drop in the ocean, but the ocean would be less because of that missing drop." It's my hope that all of us put together can flood this earth by being a little independent and doing, whatever we do, to the best of our ability.

§



GEORGE PIGACHE



*George Pigache*

Independence is such an important issue for people. After love, it is probably the thing we search for most in our lives. As a teacher working with students in a high school who are physically challenged, I have noticed that many of the students were not really interested in independence but rather, seemed to be totally dependent. Of course this is not true for everyone, but it was true for enough of them to make me very frustrated, and at a deeper level very concerned. Some students, no matter what we did to provide them with control over their movement, choices, and lives, remained completely passive. Yet of course other students were strong-willed, and obnoxiously independent as any teenager should be!

I always remember a student I will call Bill. Bill was very bright and severely disabled. He had no speech and had to move his chair by head switches. He was very interested in the world around him

and was fun to spend time with, but he used to drive us crazy. Whatever the situation, or whatever he wanted to have happen, he would not independently do the necessary task to make it occur. We would make sure he had the capability to do what he wanted to do, but he would just not help himself. We sometimes wondered if he would refuse to move out of a burning room unless someone went to get him. During our weekly staff meetings we would discuss the students, their needs, progress, and future plans. It became obvious that many of the students in the programme showed the same lack of independence. Yet at the same time, we had many students who thrived on taking control of their lives. All in all however, the general consensus was that these latter students were definitely in the minority.

The whole issue of independence has become a delicate one because of course it involves making judgements of people and the way they live their lives. Yet it is also a very important issue for parents, teachers and most importantly, for the students themselves. What intrigued us was not so much the fact that some students seemed to take control of their lives and some didn't, but rather what caused the difference between the two groups. We noticed that in one group of students the desire and ability to be in charge seemed to happen more frequently. These were the students who had become disabled as teens through an accident. They seemed to have learned how to be independent in a way that the others had not.

We had taken many of the students to sports events in the United States. We had always marvelled at the American legislation that protected the rights of persons with disabilities. The Americans with Disabilities Act made life so much easier there than in Canada. I tried to understand how this had come about there, but not here. I believe that the best people to advocate for any group of people are the people in that group themselves. In the United States, this group was Vietnam veterans. The Vietnam War was a defining time for people with disabilities in the U.S. I believe that the young men who marched off to war and came back in wheelchairs had never learned to be people with disabilities, and so were not prepared to accept life as marginal citizens when they returned home. Comparing this to our school, the students who had been disabled since birth had not been taught deliberately to be disabled but it certainly seemed to have occurred by default with many of them.

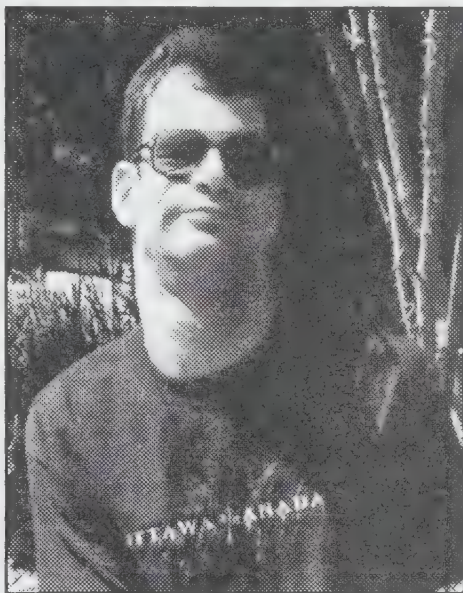
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### PAUL MARSHALL



Paul Marshall

*I believe firmly the only correct way to allow any person to reach their own level of independence is to offer them a society that includes and integrates. Personally, I was blessed to be given the chance to learn how to do things for myself in an environment where inclusion and integration went together. The following article was a presentation of mine that I gave at Ontario AAC Rounds last fall. Although I talk mostly about integration as it relates to the education system and society, I deeply feel the underlying theme is how we can as a society produce independence through inclusion.*

Well as you can see, I am up here again, presenting on something that is vital. How do we integrate AAC Users into the community? It is a huge topic to even try to discuss. I will come

right out and say, I don't think any one of us can really sit down and map out the rules and the guidelines of how integration works. Sure, there is no question that we can foster it, but I think if we try outlining every part of being integrated then quite likely we are missing a large piece of the true meaning. In my mind inclusion has to happen as naturally as possible or it isn't integration in the true form.

I am going to talk about a few things regarding community as it relates to our topic. Keep in mind, I am going to share with you my own personal reflections of many circumstances in my life. I am going to leave advocacy and lobby issues out of this discussion and talk to you on a heart-to-heart level as to how integration happens and what it means. I feel it is more beneficial for me to provide you with a personalized perspective.

I deeply believe true integration really begins within. We can make rules or guidelines until they are coming out of our ears! Without the desire and the skills for being included in the mainstream, then it is basically all for nothing. You might be thinking, "Doesn't everybody want to be integrated in every section of the community?" When we are talking about integration, it is important to point out that we are probably dealing with rights and the access to everything — not individualized desires. We cannot, and never should try, to swing anyone beyond their own desires to take part. This is a personal decision.

As a society we have to be able to see AAC consumers as a person first, with opportunities in life. Secondly, we need to always be aware that with supports from the community, we can take part as effective members. We need to develop into independent adults who have learned basic coping skills and feel some dignity in whom we are. We need to get away from the old mindset that says, if you are handicapped, society will look after you. This creates a feeling of very low self-worth. This, in turn, can develop into "learned helplessness". We need to empower the AAC community to think and to develop to their highest level of independence in their own society. I am convinced that without instilling many of the daily skills that are needed, we will always make this population more dependent than they need to be.

I am sure sometimes I sound like a broken record because often when I present, I refer back on how I was brought up. However I was extremely blessed somehow to have the right opportunities for me to be nurtured and develop. While I was growing up it seemed I was always included. I grew up on a working fruit and vegetable farm. We went to market every weekend and we always had people coming and going. So it was very easy for me to learn how to deal with the hurtful looks and words that you sometimes get when you are disabled. In a way this also helped me to realise that if I was going to master things on my own, I couldn't worry too much about how I was viewed in my society. Again because of my farm upbringing



ing, I somehow had it in me to master ways to do things, which fostered my independent spirit.

I remember often asking my two older brothers to help me with things. They somehow knew when I needed help which they were always ready to give, but often they said "Do it yourself". At the time I didn't like it, but when I look back now, they were helping me by really saying "No. You can do it yourself!" I remember cold winter days, when my brothers took my go-cart down to our creek and taught me how to steer on ice. There were countless things like this that my family did to prepare me to cope. They didn't sit down one day and say "In order to get Paul ready for the big world, we have to make a checklist." However, they did one very crucial thing. They treated me as a normal son and a normal younger brother. That, my friends, was my key or my cornerstone that set my platform for my integration into the mainstream.

Now, I wouldn't pretend to give you the picture that just because I had a great childhood meant that I didn't have struggles in my teenage years. Believe me, I did! Most of my public school education was in a regular mainstream school setting that had three classrooms for the special needs students. This was good because often we were integrated as one school body for many things. Today we have moved to the total inclusion model. Myself, I am still not sure if total integration is the right way to go (and I want to underline the words) *for all students!* It is so easy for us to get caught up in the swing of having

everybody in the mainstream of the community that we sometimes forget or socially disagree with the theme that total inclusion is not for everyone. If it is a form of dis-empowerment or making life harder for a person to function or to cope in the normal community, boy, I hope we can see the flags going up and are willing to make changes.

I will give you an example. My Mom drives a school bus. She had a special needs student on her bus for a few years. This student was in the mainstream of the education system. Through the years, Mom saw a great change in this kid and it was not for the positive. He got more and more upset because he knew that he couldn't keep up with his peer group. Mom said his behaviour kept on getting worse mostly because he wasn't getting the help which he so badly needed. The system was integrating as far as going through the motions and probably not thinking of the future for this boy. In the long run, the system really failed and turned out a boy who will not be able to reach his own level of independence. All because the system felt *total* mainstreaming was the only way to go. A very sad story!

Now an example on the positive side. I went through school with a girl with the same level of cerebral palsy as me but she could verbalize. She was able to get into the mainstream of high school and went on to Teacher's College. A few years ago, she graduated! There is a not-so-funny side to this wonderful story. She is so included in the mainstream of her community that she is in the same

boat as her peers, waiting for a full time job! I understand she is teaching part time! I haven't been in touch with her in a few months, so can't say where she is at now. This is one of the many stories that are out there on the mostly positive side.

I realize that my time is almost up and I haven't even touched on half of what I was going to present! Boy! Get these nonspeaking people in the community and you can't shut them up!

There is a growing new community that is and will greatly affect how we live today. It is called the cyberspace community or the electronic super highway! More and more we are seeing the huge transformation in how we communicate, do business, are educated, get information and the list goes on because of this new technology. E-mail and the internet are a community in themselves. Personally, most of my work is done in my study or office at home. Basically this technology evens the playing field between a so-called normal person in the everyday work force and a person with some limitations working from home. The travelling issues and further costs aren't there when we have the option of working from home. We could question if communicating with people via electronic mail is as good as getting out there where you are interacting face to face with people. There is that factor to consider. For me, as an AAC user, working by electronic means is perfect! Many times when I am trying to communicate with a person face-to-face, I go home and



send an e-mail message with my full thoughts that I want to get across. There I can take my time putting my thoughts together. E-mail to me is just another form of augmentative and alternative communication. It is that simple! We might even question if cyberspace can be classed as a community in itself. When I looked up the word "community", it didn't say anything about the *physical* presence of people!

Our society can be the jailers that put the key into the lock, to unlock the door of integration, for all types of limitations. The key which will do this is the key of understanding and the key of acceptance for all kinds of limitations. The world is still a foreign land to many of our issues as

nonspeaking and handicapped individuals. As we go into the twenty-first century, we must not be afraid to look over our shoulders to see the pit-falls of our past. At the same time we have to dream and act upon these dreams of a community, a society and a world that is willing and open to putting changes in place so all people have the opportunity to reach their own level of lifestyle suited for them.

Lastly, I want to leave you with a few questions. Why do we want to get our kids in the mainstream of life? The more important questions are: Once we have people out there, what then? Are there supports built in so they can manage the educational, employment, and housing aspects of their

day-to-day life? If so, how do we as a society keep sufficient resources in place? If these resources aren't there now, or are in question of lasting, then what? Can we or can I as an AAC user take a chance at counting on some support, when it might be history someday in the future? These kinds of questions can be pretty overwhelming and scary as we go into the new millennium, where what we dream of and what we work toward could become the reality of life for us.

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## **AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION**

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## Language .... More Dimensions Than You Think!

SHIRLEY McNAUGHTON

I realize that for some of our readers, the theme of this issue, "Why become independent and how to do it?" could at first glance seem a contradiction in terms — an oxymoron. After all, in a magazine for and about persons with severe speech and physical impairments, why would we be asking *why AAC users should and how they could* become independent? Why? Because we are facing the challenge we must always face. We must look below the surface and not settle for what may seem to be the obvious! In considering independence, we must dig deeply to recognize that being self-sufficient and self-reliant is not contingent solely upon one's physical and speech capabilities. When it comes to independence for AAC users, the critical focus must be upon independent *thinking* and independent *communication* — *expressing one's own thoughts in one's own way*. I would argue that for AAC users' *independence*, the critical component is language with its many dimensions — both receptive and expressive.

Several occurrences have contributed to this *SymbolTalk* about independence through language. First, I was invited to speak about "language" to a group of speech language pathologists, teachers and family members in Capetown, South Africa, in September. Second, I attended a lecture in October, given by Bruce Baker, entitled, "Language ...Easier Than You Think".

(Do you see the motivation for my title?) Third, in November and December, I worked with a parent and a team of professionals who were concerned about the language development of a thirteen-year-old girl and were searching for a "new" AAC approach for her, one that would contribute to her competencies in language as well as in communication. Fourth, I read with interest Paul Marshall's observations regarding his literacy development, as published in **Communicating Together**, Fall, 1998.

From these events and ongoing discussions with several colleagues, I sense a re-awakening of interest in the language capabilities of AAC users and a growing realization that neither augmentative and alternative communication (AAC) nor literacy for AAC users can be adequately examined without attention being given to language and its development. This article is devoted to a discussion regarding the *interdependence* of communication, literacy, original thinking and independence for AAC users.

It was fortunate that a week after my return to Ontario, I had the opportunity to attend Bruce Baker's lecture on language. My head was full of ideas stimulated by the discussions following my Capetown presentation. And then I heard Bruce examining the definition of language, contrasting the implications for AAC intervention arising from a *language model* versus a *needs model*, emphasizing the importance of core vocabulary, viewing vocabulary items as either picture-producers or non-picture-producers. So much of what Bruce had to say struck a resonance with my thinking! And while I may have

wished to debate the title he chose for his lecture, and he and I differ in our choice of the particular AAC system that best provides language learning opportunities for AAC users, we share many of the same "language" premises. I was delighted to discover that much of our "language" thinking is converging as each of us accumulates years of experience, even though that experience has been with different AAC systems — his with Minspeak-Words Strategy™ and mine with Blissymbolics. Bruce called for a greater understanding of language within AAC intervention. I can only hope his call will be answered.

In preparing for my look-back at language for my Capetown lecture, I first returned to the readings that have influenced my thinking since the seventies. They identify dimensions of language described in the last decades of the twentieth century that can serve us well as we enter the twenty-first!

### Definitions, Theory and Comments

Human languages make combinatorial use of discrete units at two levels of structure. At the *phonological* level they combine vowels and consonants to form words and other forms. At the level of *syntax* they use rules for combining words into phrases and sentences. This combinatorial method is so powerful that, for practical purposes, it sets no upper limit on the number of messages that languages can convey. It is the key to their expressive power. Since it operates both on the units of phonology and on the units of syntax, it has dual structure. In the terminology of the linguist, human languages are said to exhibit duality (Hockett, 1958; Lindblom, 1990, p. 227)



For speaking children, the duality of the language of their environment is applied every time they utter a new word or produce an original phrase or sentence. The “combinatorial capability” is mastered through day-to-day interaction. They learn their language through both listening to the talk of others and through talking with those in their environment. For AAC users, the duality of their native language is presented to them *receptively* as they listen to the speaking of those who interact with them. AAC users can only acquire “combinatorial capability” *expressively* if their AAC system provides duality.

Sutton (1996) examined two positions taken in the AAC field as to the acquisition of grammar (requiring combinatorial capability at both word and sentence level) by AAC users. Claim One states that the same processes and strategies are used by AAC users as by normally speaking children and relies on theories of language acquisition that focus on linguistic input and comprehension, rather than upon children’s own production. Claim Two states that AAC users do not acquire the grammar of language in the same way as speaking children because they are unable to produce utterances as effortlessly and in the same manner as speaking children. This claim relies on communication-based theories in which the role of language production is emphasized. Further study of the issues raised by Sutton would be a welcome contribution to the AAC field. It is clear, however, that both positions indicate that attention to language is critical to determining the best intervention method.

Language is a highly organized, systemic means of representing experience, and as such, it assists us to organize all other ways of representing (Britton, 1970, p. 21).

The importance of language as it influences all other ways of organizing our world is an important insight. For speaking children, their constant and effortless use of the spoken language of their environment allows them to acquire the conceptual organization of those with whom they interact. For AAC users, however, many questions can be asked regarding the influence upon classification skills and conceptual organization exerted by the various graphic systems contained within their communication displays (manual or VOCA/computer-based). The type of graphic and the way in which graphic symbols are organized and displayed can lead AAC users toward a very different conceptual framework than that of their speaking peers. For example the classification of concepts as they are represented in Minsymbols differs from the classification of concepts represented by Blissymbols. And they both differ from the conceptual framework developed as one speaks in English. As a proponent of Blissymbols, I would argue that Bliss differs less from English than Minspeak, since Bliss was originally developed as a language. Training in Blissymbolics for instructors stresses the value to be derived by tapping the organization of concepts in Blissymbolics. Proponents of Minspeak™ would argue in favour of semantic compaction and the benefits to be derived from its organization of concepts. The different ways in which these two AAC systems and the many other graphic forms available could influence the development of language and cognition is an important area deserving further investigation.

A beginning examination of the language development of AAC users has been undertaken by several researchers, e.g., Kraat,

1991; Ronski & Sevcik, 1993; Sevcik, Ronski, & Wilkinson, 1991; Soto & Toro-Zambrana, 1995; von Tetzchner & Jensen, 1996. The March, 1992 issue of *Augmentative and Alternative Communication*, with guest editor, Janice Light, was devoted to papers relating to language for AAC users that had been presented during a panel discussion at the 1990 annual convention of the American Speech Language and Hearing Association (ASHA) In her editorial, Light began by emphasizing the challenge of facilitating language learning for a young client, as well as providing channels for functional communication. Her seminal article (Light, 1989) had presented an excellent and much quoted definition of communicative competence, that included sufficiency of knowledge, judgement, and skill in four interrelated areas: *linguistic competence*, operational competence, social competence, and strategic competence. While Light’s paper had a profound influence in directing the attention of clinicians and educators to the functionality and adequacy of communication and to the ability of AAC users to apply their knowledge “to perform as required given the partner, the environment, and the intent” (Light, 1989, p. 139), the same level of clinical attention does not appear to have been given to linguistic competency in North America.

In **Communicating Together**, 1992/93, a series of articles by McNaughton (1992a, 1992b), Jennische (1992), the Carolina Literacy Center Group (1993), and Nyberg (1993) presented a debate regarding language and symbols, in which the definition of language was discussed and arguments were presented for both Blissymbolics and Minspeak as they related to language development. In 1997,



Sarah Blackstone focused on language in two issues of *Augmentative Communication News*, identifying reasons why AAC users may be disadvantaged language learners, and directly stating that, "Communication is the end; language is the means. AAC devices, symbols and techniques provide access to communication and participation through language" (p. 3).

With all of the attention that has been directed toward language, why is functional communication in specific environments the single goal dominating many communication programs today? Why is so little attention being directed toward individuals' language learning within intervention programs? Could it be that AAC professionals simply lack the time to consider language development, given the limited resources allocated to AAC service provision today? Or must we dig more deeply here as well, to understand the factors underlying AAC intervention practices today? Could the answer lie in training programs for speech-language pathologists? Could it be that the challenge of keeping up with technology with its continuous innovations and wide range of options has diverted the attention of North American AAC professionals from the deeper language-related considerations underlying communication? Could it be that instructors, care givers and family members find it difficult to understand the information they are given relating to language or that they are not given any guidance regarding language development? Could it be a reticence on the part of those directly involved in intervention to dig deeply and probe underlying factors in a world that too frequently wants fast, simple solutions? Or should we be asking, "What combination of these and other factors

influences the intervention program given to each AAC user?" and "Is sufficient attention and time being given to all the factors relating to communication competence — linguistic, operational, social, and strategic?"

There is a strong need for a link between the knowledge of AAC researchers and experienced AAC professionals, and those planning and implementing intervention programs. The knowledge we have regarding language needs to be applied. It is exciting for all concerned when this link is made! And further research is critical. An important question urgently needing research attention, from the many to be addressed, relates to the impact upon language development resulting from the AAC user, prior to acquiring literacy, relying totally upon pre-programmed phrases and sentences. This individual has no opportunity to develop a combinatorial capability at either word or sentence level. Are we settling for a superficial communication "independence", one that relies heavily first, on utterances composed and selected by others and second, upon the reliability (or lack thereof) of technology?

And now, a last quotation, from Margaret Donaldson whose book *Children's Minds* exerted such a strong influence on my thinking and my teaching.

In order to handle the world with maximum competence, it is necessary to consider the structure of things. It is necessary to become skilled in manipulating systems and abstract forms and patterns (Donaldson, 1978, p. 82).

What an exciting thought to define independence — "handling the world with maximum competence"! How critical this capability is to AAC users! The structure of various communication systems and the experience it offers to AAC

users in manipulating abstract forms and combining elements at two levels is of high importance, for both linguistic and strategic competence within communication and for literacy acquisition. Our question must be, "How does the communication system's structure contribute to the AAC user acquiring competence in "handling the world"?"

The above descriptions of language highlight important features of language for AAC users — *duality* providing rules for constructing words and sentences; *structure* providing experience in conceptual organization, and *abstract forms* and *patterns*. I would argue that the AAC user who is not given a communication system that provides for these features is faced with several disadvantages. Not only do they lack the opportunity for comprehensive functional communication; they are deprived of the "world handling" competencies that a rich language base affords. And in addition, they lack the foundation needed for literacy.

Bruce Baker emphasizes the importance of core vocabulary — words that are primarily pronouns, adjectives, prepositions that (a) comprise 80% of what is spoken, (b) number 200 to 300, (c) hold our sentences together and modulate meaning, and (d) many of which are abstract (non-picturable), enabling many meanings to be referenced — as opposed to a fringe vocabulary (words, many of which are nouns, that are specific and needed in a particular environment). This core vocabulary can in turn be related to the above features of language. The ability to access a well organized *core vocabulary* and to use combinatorial strategies to construct many of the large number of words needed in a *fringe vocabulary* is a goal highly worth striving for, for every AAC user.



Relating specifically to grammatical capabilities, Susan Blockberger (1997) recommended that clinicians should:

1. ensure that the child has an AAC system that allows for the possibility of manipulating and producing grammatical morphology (e.g., prepositions, pronouns, articles, auxiliary verb forms, possessive markers and tense markers).
2. show the child how to manipulate and produce grammatical morphology on that AAC system, and
3. give the child opportunities that are designed to elicit the production of language, including grammatical morphemes. This likely will involve activities that minimize time pressure and maximize the child's interest and enjoyment. By asking the child to select and sequence grammatical morphology, we are increasing the processing demands and the time required for a communicative act. (p. 6)

There is no substitute for a well-organized communication display with graphics that enable the AAC user to learn about grammatical morphemes as they use them in interacting (conversing) with others. If the clinician can relate to the AAC user's own display as opportunities are provided to "manipulate and produce grammatical morphology" within a lesson, the capability to generalize this knowledge to day-to-day communication is built in.

### Applying the Theory Today

So how can the preceding definitions, comments and theory be applied to an intervention plan? First of all, while I do not discount many of the implications of Claim One as identified by Sutton (1996) (I do concur that much about language is learned receptively and that comprehension is an important factor to be considered), nonetheless, I support

Claim Two in its emphasis upon the importance of language production. I argue that a primary consideration of an intervention plan should be to support expressive communication that enables the learner to use his or her own communication system to produce conventional language forms. This means the provision of a combinatorial capability at both the word and sentence level, leading to the *expression of one's own thoughts in one's own way*.

For the young developing AAC user who has not mastered phonological coding and hence cannot produce new words through spelling, a system that allows elements to be combined to form words *semantically* provides the combinatorial capability at the word level. A communication display — be it a manual or computer display — providing a rich core vocabulary that includes grammatical morphemes organized by their language function provides the combinatorial capability at the sentence level. My long-term support of Blissymbolics results from the combinatorial capability of discrete units at two levels of structure (word and sentence) that it affords. Whether Bliss be accessed on a communication board, voice output device or computer, the language capability found in all human languages (Lindblom, 1990) is provided, without relying on phonological coding, a skill that typically requires longer acquisition time for AAC users to acquire. Through the provision of discrete units at two levels of structure, the "highly organized, systemic means of representing experience" (Britton, 1970) and the skill development "in manipulating systems and abstract forms and patterns" (Donaldson, 1978) follow.

The first step in the intervention program thus entails careful planning of the learner's communication display. In the program mentioned above, I have seen the development of a manual display (with which the learner will communicate through assisted scanning) that provides an excellent language (the combining of discrete units at two levels of structure) learning capability. The display includes core vocabulary along with fringe vocabulary to meet the users' interest areas, organized by categories that are understood by the user.

The second step in the intervention program is the training of educational personnel to take advantage of the language infrastructure provided by the communication display and the graphic system on which it relies. In the training program in which I have recently been involved, the emphasis was placed upon the language features of Blissymbolics, recognizing that ongoing information was available through the many Blissymbol resource books:

- two levels of structure in which discrete units can be combined — Bliss word level and sentence level
- the capability of Blissymbols to be written on blackboard and in assignments, to record messages, write letters, stories, etc.
- the grammatical morphemes within Blissymbolics — tenses, plurality, possession, marking of parts of speech (nouns, verbs, adjectives, adverbs, preposition, conjunctions, relativizers, articles)
- generativity of Blissymbolics through the combine strategy, the opposite meaning strategy, the alphabetic strategy, the "part of" strategy, the "sounds like" strategy.

### Learning from the Past

Some programs initiated today are attempting to facilitate language



development by taking new paths, relying as they do upon the environmental and needs-based communication displays. Paul Marshall's article in the last issue of **Communicating Together** provides a good reminder that much can still be learned from earlier AAC programs regarding *language-based* communication boards. When Paul was introduced to Blissymbols at the age of twelve years, the Blissboard he was given was organized according to the Fitzgerald Key and provided a language structure for an excellent language-based instructional program. Paul was fortunate indeed that his teacher, Barbara Rush, took full advantage of the language learning afforded by Blissymbolics. In his article in the Fall, 1999 issue of **Communicating Together**, in which he talks about his own literacy acquisition, Paul describes the "foundation" that Blissymbols gave him for literacy. In particular, he mentions sentence structure, plurals, proper endings and other grammar rules. "Bliss teaches a whole host of language capabilities that flow easily into the world of print" (Marshall, 1999, p. 22). It is interesting how Paul, in looking back, summarizes the two approaches that Sutton has identified, "Teach them to listen to people, to understand how words and sentences are strung together. . . . No doubt what improved my literacy was sending and receiving e-mail messages and writing articles and presentations. Plus, I am always writing and reading and I learned to be a student of books" (Marshall, 1999, p. 22). Paul learned and continues to learn language both receptively (Claim One, Sutton, 1996) and expressively (Claim Two, Sutton, 1996). First, he used Blissymbols; then he applied what he had learned to the world of print.

His personal experience tell us much about the value of a language foundation as we enjoy his writing and his thinking today!

Paul was not the only student to benefit from a language approach to communication in the seventies! A study undertaken in 1974-76 involving 157 Blissymbol users in 32 different settings in Ontario and some American states (Silverman, McNaughton & Kates, 1978) examined many language-related variables. The subjects ranged in age from two years to over thirty years with a majority of the sample (78%) being in the age range from six to fifteen years. The study contained a coding and analysis of the best and typical utterances for over half of the subjects. The recording of utterances was done at the end of each year of the study by a teacher, speech-language pathologist, mental retardation counsellor or psychologist in the various settings. The results from this analysis showed a mean of 6 symbols per "best" utterance in 1974 (range of 1-17) and a mean of 9 symbols per "best" utterance in 1975 (range of 2-17). An examination of "typical" utterances showed a mean of 4 symbols (range of 1-11) in 1974 and a mean of 5 symbols (range of 1-15) in 1975 (Silverman et al., Part 2, p. 59). Sentences were found to contain the following grammatical components: agent, action, object, locative, ablative and dative. They were presented in statement, compound statement, question and imperative forms. They included time references, articles, conjunctions, and prepositional phrases. Most noteworthy in analysing the construction of words was the extensive use of the "combine strategy" to create symbols for concepts that were not available on the communication board and the

use of the "opposite meaning strategy" to arrive at antonyms for words on the communication board. Within the Silverman et al (1978) study, the variable that related most highly to ratings of symbol proficiency was the "ability to deal with situations when the meaning of the message was not comprehended by the listener". It is interesting to note the scale used to measure this variable:

6. *Spontaneously* offers alternative symbol message.
5. *Independently* produces alternative symbol message with effort.
4. Responds with alternative symbol message when reminded.
3. Responds with alternative symbol message when directed by specific questions.
2. Environmental clues accompany first message.
1. Repeats first message.
0. No attempt to deal with situation.

I wonder what would happen if we applied the same criteria and the above rating scale to the communication of AAC users today. Are there those who would argue these measures should no longer be applied? Are there those who are either applying similar language-related measures or measures they would argue are superior, who would like to offer their thoughts to **Communicating Together's** *SymbolTalk* in the next few months? Submissions will be most welcome! I believe a serious look at the language learning provided to AAC users can best be accomplished through examining the graphic system, display organization, instruction and experience we provide within intervention programs. I invite others to add their ideas to this topic.



## In Closing

Let's not try to make our examination of language too simple or expect it to be easy! There are too many dimensions to consider! Rather, let's enjoy the richness of the communication, literacy and "handling of the world" to be derived from an in-depth understanding of language. To gain the knowledge we need for responsible intervention, let's try to understand the interaction between as many of the dimensions as possible! And let's keep in mind that the goal is AAC users *expressing their own thoughts in their own way*. This is independence for AAC users! And, in response to our initial question, "Why become independent?", the answer can be stated simply — because this is the essence of our development as human beings!

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# CONTENTS

## FEATURE

- 2 Why Become Independent and How to Do It? PETER LINDSAY, SHIRLEY McNAUGHTON  
ANN RUNNING, AND MIRIAM RUNNING

## AS COMMUNICATION CHANGES

- 8 Smelling the Flowers ALDA STEPRANS  
AUDREY McGEE

- 8 READERS WRITE SHELLEY DEEGAN

## CLINICALLY SPEAKING

- 9 Baby Steps Towards Independence TRACY SHEPHERD

## REFLECTIONS

- 11 Presenting Independence NOLA MILLIN

- 14 PERSPECTIVE GEORGE PIGACHE

## PAUL'S PULPIT

- 15 Independence through Indecision PAUL MARSHALL

## SYMBOLTALK

- 18 Language — More Dimensions Than You Think SHIRLEY McNAUGHTON

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